Autism Commission Meeting Minutes

December 9, 2019 – 2:00 p.m.–4:00 p.m.

One Ashburton Place, Boston, MA

Present: Carolyn Kain, Jane Ryder (DDS), Elizabeth Morse (DDS), Rep. Christine Barber (HOU), Johanna Wakelin for Sen. Joan Lovely, Diana Amaral for Rep. Elizabeth Poirier, Ann Reale (EOE), Sacha Stadhard (EOL), Christine Hubbard, Kathy Sanders (DMH), Amanda Green for Russell Johnston (DESE), Toni Wolf (MRC), Amy Weinstock, Bronia Clifton (DHCD), Julia Landau, Michele Brait, Joan Butterfield (DPH), Katherine Canada (DCF), Kathryn Downes (ELD), Dania Jekel, Ann Neumeyer, Sue Loring, Vinnie Strully, Kate Ginnis (MassHealth), James Vander Hooven, Jo Ann Simons, Judith Ursitti, and Dan Burke.

**Welcome - Review and Approval of Meeting Minutes from September 26, 2019**

Commissioner Jane Ryder called the meeting to order and welcomed the Autism Commission members. There are new members to the Autism Commission and Commissioner Ryder asked that all members go around the table and introduce themselves. She asked the commission members for a motion to approve the minutes from the meeting in September. Christine Hubbard pointed out one minor change to the minutes, and with that change, the minutes were approved unanimously.

**Discussion on Draft 2019 Annual Report**

Ms. Kain gave an overview of the draft report and noted that the structure is similar to last year’s report. Updates included in draft report:

* Data on number of newly eligible individuals
* Highlights on the FY20 budget
* MassHealth and ABA services – this relates to the previous recommendation to expand coverage of ABA services for individuals over 21 years of age. There is currently no plan to expand this coverage by MassHealth
* Interagency agreement between DDS and DMH and the number of consultations (81)
* Data from MRC
* Ongoing work by housing and employment subcommittees

Ms. Kain stated that this meeting is the opportunity for members to ask questions, provide input, and to makes any suggested changes or additions to the report before it is finalized for vote at the February 2020 meeting.

*Questions/Comments*

* Page 4 – Ms. Landau asked if the newly eligible data could be broken down further by race, ethnicity and primary language spoken at home. Commissioner Ryder said that information is not currently available and she would ask about it being included in the future.
* Page5, sec. IV – Ms. Landau asked if there could there be an update on the number of individuals who have received AAC devices through MassHealth and could that number be broken down by race, ethnicity and primary language spoken at home. It was asked that it be included in the report. Ms. Kain stated that the information Ms. Landau requested was part of the new recommendations by the Birth to 14 Subcommittee and the information that subcommittee was requesting as part of its work. Ms. Landau asked for any current information on this issue to be added. Ms. Kain said she would contact MassHealth.
* Page 5, sec. IV – Ms. Hubbard asked for breakdown of the number of individuals, by age, that received ABA services through MassHealth in FY19. Ms. Kain said she would request that information but it was expected to be grouped by ages.
* Page 4, sec. II – Ms. Jekel asked if the 1,313 newly eligible enrolled in DDS services, are they receiving services? Commissioner Ryder answered yes, they are receiving services.
* Page 5, sec. V – Ms. Ursitti discussed Autism Speaks and a focus of work around mortality and shorter life expectancy related to co-morbid disability (ASD and mental health). She asked about the number of individuals (ASD/mental health) that apply to DMH and are not found eligible – is there any information as to why they are not found eligible at DMH. Dr. Sanders replied that they do not collect that data, data is collected only for individuals found eligible. She will follow up on this question. DMH does collect mortality rates and they see a 25-30 year shorter lifespan – substance abuse issues has driven the age down for individuals.
* Ms. Kain discussed the pilot program that was initiated by DDS and DMH under the adult subcommittee – the pilot program helped individuals with ASD and mental health issues, who were self-isolating, become more engaged with targeted efforts.
* Ms. Ursitti referenced the 2018 Autism and Health Report and co-morbid health issues

Ms. Kain discussed the recommendation part of the report and said that there are no requirements for any new recommendations and the work of the subcommittees is ongoing. She noted that other priorities are listed at the end of the report.

*Questions and Comments on updates on Recommendations*

* Commissioner Wolf discussed the merging of Workforce Development with 14-22/employment subcommittee and that a representative from the Department of Labor will join the subcommittee starting in January. Ms. Stadhard from EOL commented on adding an additional layer of education for employers and on staff training at Career Centers on the needs of individuals with ASD. She is excited to have an opportunity to work together.

Mr. Strully brought up the issue of ABA Center Based Programs and that there is no oversight or license required for these programs, it is growing concern for many reasons, including safety of children and the quality of services. Some of the Center Based Programs are owned by young BCBA’s and some by Venture Capital Investors looking to take advantage of the lack of licensure required. Ms. Kain recapped the meetings and discussions she had had with various state agencies about this issue, and that she has reviewed the regulations of EEC, DDS, DPH and DMH as part of that work. There has not been a final resolution about which state agency is the most appropriate to oversee these programs. There have been changes in leadership at EEC and it is on Commissioner Aigner-Treworgy’s radar. There is agreement that these programs need to be regulated but they do not fit with EEC’s current regulations. Undersecretary Reale commented that a meeting occurred between her staff and DESE – the issue is complicated and she made a commitment to have some information on the status for the Autism Commission at its next meeting in February 2020.

*Discussion*

* There needs to be more urgency on this issue.
* Insurance companies are missing and need to be part of the conversation as they are paying for the services
* Private equity firms are reaching out to providers - these firms are buying smaller organizations and want to capitalize on this now but there is a major concern with the quality of services and how that will diminish if private equity moves into this profession
* Ms. Ursitti commented that she sees this issue in other states as part of her work with Autism Speaks. Many families have been waiting for these services and find that CBP are good and meeting their needs but there is still concern for long term quality once they continue to expand
* BCBA’s are forming unions because they are concerned with unethical practices
* Questions on why there can’t be oversight by EEC since the CBP are serving children
* We should look at the safety and health issues, with quality of ABA services being the responsibility of the LABAs and the payers
* People working in the CBP are licensed and there are quality services being provided but oversight is important
* If these smaller CBP’s are sold to Venture Capital firms, the quality of services will change
* EEC is most aligned with this issue but there are at least 2 other state agencies who could be involved and they need to be at the table for this discussion
* It was asked if the Commission could make this a recommendation and take a vote. Ms. Kain will work with EEC and other relative state agencies to draft a recommendation and it was agreed by members of the Autism Commission that they will wait for an update at the February meeting to vote on a recommendation related to Center Based Programs.
* Ms. Kain will gather feedback from state agencies on realistic timelines and any financial impact on the state agencies
* Mr. Strully proposed having providers and a representative from a Venture Capital firm present at the next meeting to help educate the members on Center Based Programs. He is attending a conference in January and will learn more on this topic. He will put together a 20 minute presentation for the meeting in February to help educate the members about the process

*Discussion on the merge of 14-22/employment and Workforce Development Subcommittees*

Ms. Kain gave a brief history of the Workforce Development Subcommittee, and the update that it has been inactive following both co-chairs stepping down. Ms. Kain stated that the issue of workforce development is not exclusive to ASD population, it is very broad with many types of care providers needed. Commissioner Ryder commented that DDS is working on a technology forward initiative that is related to the workforce issue. They are looking to have this in the FY20 budget and she will continue to update the Commission.

Ms. Hubbard discussed adults and different qualifications needed to work with autistic adults – especially those with behavior challenges – there are certain traits/aspects of ASD that are different than other disabilities.

* Birth – Fourteen Subcommittee is working on the workforce challenge
* Ms. Kain discussed having all subcommittees include the workforce challenges in their work as it relates to their respective subcommittee’s focus
* Mr. Burke asked if Autism Commission could be updated on the work being done on workforce issues. He has been in this field for 36 years and sees this workforce shortage as a crisis and suggested that all subcommittees address this issue as part of their work
* This is a good opportunity for Higher Ed. to be pulled into the discussion on ways to encourage young students to become interested in this work as a career path
* Mr. Vander Hooven, from Wachusett Community College, discussed looking at data and the reality for their students who are savvy on the return for their investment in education. He will plan on going back to the college and have discussions on this issue with the presidents of Wachusett Community College. He also stated that he is unsure of which subcommittee would be the best fit for him, but he is willing to join the one that would best fit the committee needs
* Discussion on private partnerships, paid tuition to encourage to go into this field, loan forgiveness – MassHealth is doing work in this area
* Ms. Simmons discussed the need for technology to assist with addressing the workforce shortage and to better enhance the lives of individuals and supplement the staff

*Other topics of discussion*

* Page 14 – Children with ASD in DCF care – Ms. Jekel commented that her organization sees more specifically when the adult with ASD has a child with ASD there is more involvement with DCF and how can this be addressed
* Ms. Canada responded on new recommendation #3 –DCF is are aware of parents who are on the spectrum. She asked to consider when developing a training, what is the problem that needs to be solved? DCF is at the table and they want to make sure that their practices are the best. She discussed a collaboration between agencies rather than a single training since the needs of each child and family differ and that by working together DCF and DDS can problem solve based on the particular challenges as family is experiencing.
* Ms. Kain mentioned that she previously did a webinar for DCF on ASD in young children.
* Ms. Landau discussed the Birth -14 subcommittee and a 4th recommendation of collecting data broken down by race, ethnicity and primary language. It was captured in the minutes but not in the report. Ms. Kain said she will look at the minutes and the recommendations in the report from the Birth to Fourteen subcommittee.
* Ms. Landau discussed the waitlist for ABA services and families who do not speak English – there are no easy solutions but would like the report to include and address this issue. Ms. Kain asked that Ms. Landau share any specific information she has on this issue since insurance providers and MassHealth require providers to meet this need.
* Page 13, #2 – priorities of reduced wait times – this is across the age span and not just for younger children. Adults have difficulty getting a diagnosis – can we expand the age on this priority. Ms. Kain responded that it could be added to the Adult Subcommittee work and she will further discuss with the chairs about whether they intend to draft a specific recommendation or priority.
* Ms. Jekel added that we should look at the format of the report across all recommendations as there are certain recommendations that could be applied broadly. Ms. Kain suggested that Ms. Jekel send her any suggested changes in this regard.
* Ms. Kain said that she would make the suggested edits and additions made at this meeting (based on additional information she requests and receives from state agencies), and the next meeting will include a vote to approve the report.

With no further business to discuss, Commissioner Ryder made a motion to close the meeting.

The meeting ended at 3:45 p.m.